



WRITTEN TESTIMONY OF:

Hospice and Palliative Care Association of New York State
(HPCANYS)

PRESENTED TO:

The Joint Health Legislative Budget Hearing

ON THE SUBJECT OF:

2023-24 Executive Budget Proposals on
Health Care and Priority Inclusions

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Introduction

Thank you to Chair Krueger, Chair Weinstein, and members of the Committee for providing me with an opportunity to present recommendations from the Hospice and Palliative Care Association of New York State (HPCANYS) on the 2023-2024 Executive Budget.

Hospice is an essential part of the healthcare continuum. It is a team-oriented approach to end-of-life care that offers expert medical care, pain management, emotional, and spiritual support expressly tailored to the patient's needs and wishes. Hospice has long addressed social determinants of health, caregiver wellness, and family participation in the plan of care. Hospice promotes quality care for those with a life-limiting illness, and supports patient choice and informed decision making, allowing patients with a life-limiting illness to make the decisions for themselves that they deem best.

It is also associated with significant savings in health care expenditures. Utilization of the hospice Medicare benefit directly translates to savings of Medicaid dollars and family out-of-pocket spending at the end of life. The estimated one-month out-of-pocket savings associated with hospice is \$670, which represents roughly 20% of the monthly income of the lowest third of older adults in the United States. Further, the \$670 estimated savings represents an almost 75% reduction in out-of-pocket costs compared with older adults who did not receive hospice care.¹ Therefore, every effort the State invests toward increasing hospice utilization is both morally and fiscally justified. The research and data points consistently show that when hospice is appropriately funded and regulated, hospice represents the best of health care.

The Executive Chamber, Legislature, and Department of Health have repeatedly stated their commitment to improving and strengthening the State's hospice and palliative care infrastructure. However, policy and financial support has been erratic. As a result, New York State has consistently ranked behind the rest of the country for hospice Medicare utilization, with a current ranking of 51st in the nation. Moreover, the COVID-19 pandemic further highlighted that the current health care system in New York does not fully support nor promote patient access to hospice and palliative care services.

As the only statewide association that exclusively represents the State's licensed hospice and palliative care providers, as well as other organizations and individuals concerned with care for

¹ Aldridge MD, Moreno J, McKendrick K, Li L, Brody A, May P. Association Between Hospice Enrollment and Total Health Care Costs for Insurers and Families, 2002-2018. *JAMA Health Forum*. 2022;3(2):e215104. doi:10.1001/jamahealthforum.2021.5104



patients at the end of life, HPCANYS is in a unique position to identify barriers to care and challenges to sustainability. We offer the following commentary on key Executive Budget provisions for your consideration, and propose additional solutions that will support the State in its endeavors to reform care for those with a life-limiting illness, logically building on last year's successes, and ensure effective implementation of policy initiatives unanimously approved by the Legislature.

Executive Budget

Several provisions in the Executive Budget will impact hospice care. Perhaps the most obvious are provisions revising the State's certificate of need laws, which govern the establishment of healthcare providers, including hospice. This issue is especially fraught at a time when other states are wrestling with an influx of unscrupulous for-profit providers that prioritize revenue over patient care, prompting some states to impose additional restrictions on the unregulated expansion of hospice. New York has not yet faced the same influx, but with the recent veto of a bill (A.8472/S.9387 of 2022) that would have prohibited the establishment of new, for-profit providers, it can be assumed that the Department of Health will be receiving a number of new applications in short order. The changes to the certificate of need rules necessary to address this require a comprehensive and detailed review of the applicable laws that cannot be accomplished in the context of budget negotiations, as HPCANYS shared in its white paper with the DOH and Executive in the Fall of 2022. Accordingly, we request that the Legislature reject this language, and pledge to work with the Executive and Hospice advocates on these reforms as part of a larger effort after the budget is finalized.

Similarly, the provisions in the Executive Budget concerning the Health Care Worker Bonus and Fair Pay for Home Care must include sufficient support for hospice. Last year's efforts failed to include all hospice team members as eligible titles, and failed to provide funding for Medicare providers like hospice that would allow them to match salary increases granted to Medicaid providers, effectively harming hospice by placing it at a competitive disadvantage relative to other providers. This year's budget must remedy that (including the \$35 million proposal recommended below).

In contrast, we support the Executive Budget proposal to establish a new \$1 billion Statewide Health Care Facility Transformation Program to fund capital projects for eligible health care providers, including hospice. We would ask that 10% of such funds be set aside for hospice.

We also support the Executive Budget initiatives focused on removing administrative barriers to allow physician assistants to work within the full scope of their education, training and



experience, and the proposal to allow New York to join the Interstate Medical Licensure Compact.

Finally, we support increasing the proposed 5% nursing home rate increase to 20%. Hospice residence reimbursement is based on the regional nursing home rate. Hospice residences, already a rare commodity in New York State, are closing because they cannot be sustained under current reimbursement rates. Funding for this proposal will allow New York State hospice residences to keep their facilities open and to continue providing care to patients at the end of life.

New Proposals

In addition, the Association requests that the following four initiatives be included as critical components of the New York State 2023-24 Enacted Budget to increase hospice and palliative care utilization and offer significant cost-savings to the State, and that our recommendations be considered as vital action items to preserve the State's hospice integrity and infrastructure.

Advance Care Planning: Development and Implementation of Statewide Campaign

Budget Request: \$2 million start-up for a multi-year campaign

Funding is requested for the development and implementation of the statewide Advance Care Planning Campaign signed into law by Governor Hochul after unanimously passing in both the Assembly and the Senate in 2022 (Chapter 406). This new law helps to assure that choices regarding one's care during critical moments are honored.

Whether someone is facing an acute illness, a long-term chronic illness or a terminal illness, advance care planning can help alleviate unnecessary suffering, improve quality of life and provide better understanding of the decision-making challenges facing the individual and his or her caregivers. An advance care plan can be used at any stage of life and should be updated as circumstances change. As COVID-19 highlighted, more individuals recognized that they were not prepared should they become seriously ill. Individuals need to be educated about the options that exist to help keep them comfortable through an illness, how to make informed decisions about what treatments they want to pursue, how to talk with your doctors, and what Hospice is and how to access it.

We support empowering the public with the knowledge, so that they can choose what is right for them. Barriers to advance care planning include lack of awareness, denial of death and illness, confusion, and cultural differences. These barriers are best addressed through outreach,



education, and discussion. There are a myriad of issues that limit access and widen the gap in health disparities including regulatory, reimbursement, and educational issues. Public perception of hospice and palliative care remains a roadblock to access. In communities of color, additional challenges include language barriers and culturally-based apprehension regarding cessation of curative treatment. Further, individuals from minority groups are often diagnosed with diseases at late stages and have worse outcomes, leading not only to higher mortality rates, but also affording them less engagement in advance care planning, leading to an under-utilization of hospice care. A coordinated and comprehensive effort is needed to help address cultural and linguistic barriers to understanding the benefits of hospice and myths about what hospice is and what the benefit is not. Culturally competent communication and education on advance care planning, hospice, and palliative care, delivered by leveraging the use of community partners and stakeholders will not only improve hospice utilization but help to close the gap in health equity.

Despite the benefits offered by hospice, there is still a significant gap in awareness and understanding about this benefit including who is eligible and when it would be appropriate. This gap exists not only with the public, but also with the greater health care community. There is a critical need to increase this awareness in both the public as well as in the health care system so that more individuals have the option access this end-of-life care.

A multiyear financial investment is needed to create a comprehensive stakeholder coalition to develop a public campaign on health care communication and advance care planning. The initiative may include media, social media and material distribution, education of State employees, long-term care facilities, other care providers, and faith-based leaders.

NYSDOH Director of Hospice and Palliative Care Access and Quality
Budget Request: \$400,000

A.8881 (Wallace) / S.8206 (Hinchey) unanimously passed in 2022 in both houses², would have amended the Public Health Law to establish the “Office of Hospice and Palliative Care Access and Quality” at the New York State Department of Health. The bill had broad bipartisan support with 29 sponsors in the Assembly, 6 in the Senate. However, the Governor issued a veto the day after Thanksgiving citing duplicative State efforts and a matter better addressed through the Budget process. Hospice expertise and insight is essential in the development of end-of-life care policy and regulations. Hospice providers, staff and patients would finally have the attention and support necessary to ensure full and fair access to hospice services. We respectfully request the DOH initiative be funded in the 2023-24 budget, and that the State affirms its commitment for all

² Senator Michele Hinchey reintroduced this initiative on February 16, 2023. See S4858



people in our State with a serious illness who are nearing the end of life.

This initiative is grounded in normative, real-life stories that illustrate the consequences of not having appropriate expertise and representation at the Department. While we appreciate that the Department may think the industry's needs can be met through other avenues, it must be acknowledged that the Department has failed, and consistently continues to fail, to remember hospice on multiple occasions. We certainly recognize the magnitude of the Department's duty, and do not attribute this failure to any negligence on the part of the Department staff, but without ensuring that someone is involved in decision-making whose sole purpose is to think about the hospice sector, that failure will continue.

The State is failing in its role to care for seriously ill New Yorkers. This failure can no longer go unacknowledged and must be immediately reconciled. While the Association appreciates the intent and ambition of the Master Plan on Aging and the promise of appropriate hospice representation, the State has decades of failures in embracing hospice and palliative care as essential and important space on the care continuum. We request that appropriate representation be addressed in the 2023 Budget, as the Executive advised in her veto memo on November 23, 2022.

Caregiver and Workforce Supports for Hospice

Budget Request: \$35 million for CHHAs and hospices, with no less than 10% earmarked for hospice

The recommendations we advance could increase access to hospice, decrease overall health care expenses, and perhaps more importantly provide information, education, and support to hundreds of thousands of New Yorkers who will be facing a serious life-limiting illness this year. However, in order to meet the demands of caring for an aging and seriously ill population there must be an adequate workforce. To date, hospice and palliative care workers have not received the support from New York State workforce efforts.

The healthcare worker crisis extends far beyond hospital walls and frequently delays discharge from the hospital to a more medically appropriate setting. Sometimes these delays can mean the difference for someone wishing to die at home versus dying in the hospital. The problem is worse in "home health and hospice deserts" – communities already hit hard by health disparities. Hospice in New York is 51st in the nation for hospice utilization, and a shrinking workforce may make it even harder for people to access this "gold standard" of care. Unfortunately, the past has proven that without explicit guidance and allocation, monies



intended to address the severe healthcare worker shortage are never seen by hospice workers or organizations.

Although billions of dollars have flowed into the State's Home and Community Based Services ("HCBS") from the Federal Government, not one cent has been invested by New York State in the hospice and palliative care workforce.

While Governor Hochul has ordered that a New York State Master Plan for Aging shall coordinate existing and new state policy and programs creating a blueprint of strategies, it is critical that serious illness care providers be included in all conversations. Our Association has written and presented numerous advocacy documents outlining how the State has consistently failed to consider palliative care and hospice in policy decisions and regulatory oversight. We respectfully assert our ongoing need for time-sensitive inclusion, and request workforce dollars to meet the immediate need of seriously ill New Yorkers.

The Executive's recently announced Caregiver Initiative also provides opportunity for progress in addressing the need for caregiver supports. An estimated 6.6 percent of American adults aged 55 and older have no living spouse or biological children, according to a study published in 2017 in *The Journals of Gerontology: Series B*. (Researchers often use this definition of kinlessness because spouses and children are the relatives most apt to serve as family caregivers.) At the end of life, researchers at Mount Sinai in New York reported that people without partners and children had received fewer hours of caregiving each week and were more likely to have died in nursing homes. Few have long term care insurance or can afford the costs, yet most will also be unable to pay for sufficient care out-of-pocket. Many do not have incomes low enough to qualify for Medicaid. The State needs to address the issue, and there is little time to waste. More needs to be done to support the caregivers at the end of life who are vulnerable themselves to mental and physical health issues. We ask that these caregivers receive adequate attention during these conversations, as the alternative to having a caregiver in the community at end of life is death in a hospital setting. Not only is this not in line with the wishes of the majority, it wreaks havoc on an already stressed and overburdened healthcare system.

Our Association, along with home and community based services stakeholder allies, requests a combined \$35 million (with no less than 10% to be allocated specifically for hospice) for the implementation of caregiver and workforce initiatives. With their allocation, hospices initiatives could include:

- I. Implementation and evaluation of the impact on caregiver's for Consumer Directed Personal Assistance Program support while on hospice;



- II. Recommendations and pilot projects related to regulatory modifications/changes for direct care workers still in need of public assistance (i.e. Reductions in the “countable income” for essential workers);
- III. Pilot Projects or initiatives related to transportation barriers, career paths within the community health care arena, and social-environmental support programs for the workforce;
- IV. Regional Coalitions to determine current workforce “deserts” with critical needs. Members of the Regional Coalitions to include: Local DSS, Local Public Health, Regional OFA, Providers, Educational Institutions, Associations, and other Stakeholders;
- V. Implementation of The New York State Palliative Care Education and Training Council 2018 recommendations, up to and including the establishment of designated Palliative Care Centers of Excellence and practitioner resource centers.

Integration and Expansion of Advance Care Planning Documents Registry to DOH

Budget Request \$75,000

In hospitals, hospice, and nursing homes, the Medical Orders for Life Sustaining Treatment (MOLST) form may be used to issue orders to medical personnel concerning a patient’s wishes for specific life-sustaining treatment. In the community, the form may be used to issue nonhospital Do Not Resuscitate (DNR) and Do Not Intubate (DNI) orders, and in certain circumstances, orders concerning other life-sustaining treatment. The signed MOLST form provides instruction to emergency services personnel as to how to proceed with care and transport upon the scene of an emergency call. Patients are instructed to take the form as they travel to different health care settings to assure their wishes are followed in the next healthcare setting.

Utilization of health information technology to enhance availability of medical records and other information has increased dramatically in recent years. This is also true for advance care planning documents, especially Medical Orders for Life Sustaining-Treatment (MOLST) forms. Many states have developed or are considering the development of MOLST registries or other electronic solutions for document completion, storage, and access for health care professionals.

Registry development transforms treatment preferences into actionable medical orders that can be used across treatment settings. One barrier to implementing advance care planning documents is accessing them in a timely manner in emergency medical situations when they are most needed. MOLST orders in particular can be critical to making important determinations. There may be only minutes in which to make these vital decisions. The development of



electronic registries of these documents and the wishes or medical orders they contain alleviates this barrier.

The NYeMOLST system is the first operationalized web application for both MOLST or POLST form completion and electronic retrieval in a registry nationally. The tools and features in the eMOLST system ensure a standardized process is used for MOLST conversations. When the physician, nurse practitioner or physician assistant electronically signs the eMOLST, a copy of the medical orders and the discussion automatically becomes part of the NYeMOLST registry and is available in all settings and across care transitions. eMOLST may be used with paper records, integrated in an EMR or hybrid system, as well as Health Information Exchange (HIE), allows for electronic signature for providers and for the form to be printed for needed workflow in the paper world. eMOLST serves as a risk management tool to provide access to properly completed eMOLST forms across care transitions statewide and ensure patients' preferences for care and treatment are honored in all care settings. eMOLST is free, available statewide, and accessed at NYSeMOLSTregistry.com.

New York State MOLST electronic forms are currently contained in a registry maintained and administered by a health insurance company independent of the Department of Health ("DOH"). This benevolent action is admirable, however, it leads to HIPAA concerns from health systems who refuse to use electronic MOLST forms not protected or accessible through the Statewide Health Information Network for New York ("SHIN-NY"). The SHIN-NY enables collaboration and coordination of care to improve patient outcomes, reduce unnecessary and avoidable tests and procedures, and lower costs. This results in health systems creating system-specific access that is unavailable to EMS providers or others serving the individuals in an emergency.

An official statewide integrated electronic registry would offer patients with frailty or advanced progressive illness an important means of helping to ensure that their wishes for medical treatment will be known and honored in times of crisis. This option is key criteria for "What Matters" in an Age-Friendly system and, respectfully, too technical an issue to be addressed within the confines of the Governor's Master Plan on Aging.

Today, the SHIN-NY connects 100% of the hospitals in New York State, over 100,000 healthcare professionals, and represents millions of people living in or receiving care in New York State. Without the eMOLST registry connection to the SHIN-NY community EMS, hospital Emergency Care physicians and others are prevented from quickly and easily accessing the physician orders for life sustaining treatment in the critical timeframe of emergent medical care and patient choice.



A statewide registry overseen by the DOH would offer patients with frailty or advanced progressive illness an important means of helping to ensure that their wishes for medical treatment will be known and honored in times of crisis at any location.

The Centers for Medicare & Medicaid Services (CMS) State Medicaid Director's Letter 16-003 updates guidance on the availability of CMS 90/10 funding that may be used to support POLST registry development and integration with HIE organizations. It is time for New York State's health informatics infrastructure to be updated and provided the responsibility for assuring the proper access and regulatory upkeep of critical end-of-life medical orders.

The Association's 2023 budget request provides planning phase-in funding for the comprehensive integration of the eMOLST throughout New York State by leveraging CMS "Meaningful Use" dollars, the SHIN-NY, and other existing DOH Health Information Technology assets. The plan includes steps for the expansion of Excellus BlueCross/BlueShield eMOLST to systems across the State.

Conclusion

Our requests represent a well-reasoned, comprehensive yet cost-conscious set of proposals that will help advance and improve the quality, access, and delivery of serious illness care for all New Yorkers, especially the seriously-ill and dying in our community and congregate care settings. Our 2023-24 budget requests will complement our ongoing advocacy priorities, save the State Medicaid dollars, and decrease the out-of-pocket costs to families in an individual's final stage of a life-limiting illness. Building on the historic progress made last year within our State to care for the seriously ill and dying, HPCANYS looks forward to continuing our work with the Executive Chamber, the Division of Budget, the Legislature, and the Department of Health to improve the utilization of hospice and palliative care services as the State continues to develop a sustainable health care infrastructure. Our goal is aligned with the State's obligations to provide more cost-effective, coordinated, and quality care to New Yorkers at end of life. Such goals must be met as the State moves forward with other end of life option initiatives.

Respectfully Submitted on Behalf of the Hospice and Palliative Care Association of New York State by:

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